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Exploring the Nature of Illness Perceptions in People with End-Stage Renal Disease

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Summary

Background: Diagnosis and treatment for End-Stage Renal Disease (ESRD) results in vast lifestyle changes and restrictions. Despite the high prevalence of depression in ESRD patients, the psychosocial impacts of ESRD are still often overlooked. Illness perceptions enable patients to make sense of their illness and are closely associated with depression. Due to the high levels of depression within ESRD, this study sought to understand the nature of illness perceptions in people with ESRD.

Methodology: In this qualitative study eleven patients were identified through hospital and online patient support groups. Semi-structured interviews were audio-taped, transcribed and analysed using grounded theory techniques.

Results: Three themes emerged from the data: renal conflicts, forced adjustment and coping. The main dimensions of illness perception discussed by participants were consequences, control, timeline and identity.

Conclusion: The results of this study have practical implications for informing practitioners about the psychosocial effects of ESRD diagnosis and treatment.

KEY WORDS: Illness perception; Chronic Kidney Disease; Haemodialysis; Psychosocial.

BIODATA

Jessica Rees graduated from the University of Liverpool after completing her Masters in Psychological Sciences (Clinical and Health Psychology), she now works as a research assistant. She developed her qualitative research skills working on other health psychology projects investigating coping mechanisms in people with a variety of chronic illnesses. This work refined her research focus into psychological adjustment to renal disease.

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Conflict of interest

The authors do not have any conflicts of interest to disclose.

Author contributions

JR: Principle Project Leaders, conceived the study, participated in design and coordination, undertook interviews, drafted manuscript, read and approved final manuscript.

JR, LS: Principle Project Leaders, conceived the study, participated in design and coordination, helped draft manuscript, read and approved final manuscript.

JR, LS, JC, WD: helped to draft manuscript and approved the final manuscript.

Background

End-Stage Renal Disease (ESRD) is a term used for patients entering the final stages of declining kidney function. As kidney functionality is irrevocable, a primary means of removing accumulating toxins from the body is through renal replacement therapies (RRTs). RRTs are essential for survival as ESRD is fatal if left untreated (Department of Health 2004) by transplantation, peritoneal dialysis (PD) or haemodialysis (HD) which can be completed at home or in hospital (McMillan 2014). Important differences have been reported in terms of emotional distress and quality of life across RRTs (Cameron *et al.* 2000). In addition to illness and treatment demands, patients are required to adjust to the psychosocial impacts of the disease including changes in body image, social relationships and employment (Mariotti & Carvalho 2011). The aforementioned lifestyle changes have been found to gravely effect the psychological wellbeing of patients and their families (Waters 2008) with depression in ESRD significantly higher than the general population (Chilcot *et al.* 2010).

A culture of acceptance and tolerance of psychopathologies such as anxiety and depression has been found in HD patients, resulting in low levels of professional help-seeking behaviour (Cukor *et al.* 2007). This is significant as the psychosocial effects of ESRD are still often overlooked comparatively with other illness such as cardiovascular disease and cancer (Kaptein *et al.* 2010). Although understudied, psychosocial issues play an important role in the management of kidney disease due to its impact upon wellbeing and clinical outcomes (Cukor *et al.* 2007).

Theoretical Framework

One useful theoretical framework to understanding how patients attempt to manage and adjust to their conditions is The Common Sense Model of Self-Regulation (Leventhal *et al.* 1980, 1984). This model proposes people develop personal perceptions, based on cognition and emotion, which allow them to make sense of a health threat. Illness perceptions (IP) are the organised beliefs patients have about the following dimensions of illness: Identity which refers to the person's beliefs about the label of illness, and where patients acknowledge illness through symptoms; Timeline relates to the perceived duration of illness for example if

the course of illness is believed to be permanent or temporary; Consequences describes beliefs surrounding the implications of the illness which includes physical, psychosocial and economic impacts of illness; Control which surrounds beliefs about controllability and the extent to which the illness can be controlled or cured; and Cause which encapsulates a person's beliefs about illness origins or cause of the illness (Lau & Hartman 1983).

IP are an important factor in adjustment to chronic conditions (Petrie *et al* 2007). IP have been found to directly influence the type of coping strategy employed (Kucukarslan 2012) and are imperative for patients to explain and manage their illness (Hale *et al.* 2007). Within ESRD, IP have been shown to be related to a variety of health outcomes including quality of life (Griva *et al.* 2009), depression (Chilcot *et al.* 2013; Chilcot *et al.* 2011b) and mortality (Chilcot *et al.* 2011a; Parfeni *et al.* 2013). Accordingly, investigation into the IP of people with renal disease is an important topic for future research (Kaptein *et al.* 2010; Chilcot 2012) and may serve as interventional targets for treatment engagement, adherence and outcome health outcomes (Safo *et al.* 2015). To date, the vast majority of the literature has used quantitative assessments such as the Illness Perception Questionnaire (IPQ) to measure how patients perceive their illness (Moss-Morris *et al.* 2002; Chilcot *et al.* 2011b). The addition of qualitative measures has been proposed to enhance the utility of the IPQ (Scharloo *et al.* 2000). Using qualitative methodologies in addition to the IPQ has been found to provide greater insight into the idiosyncratic and dynamic nature of illness perceptions in heart transplantation (Janelle *et al.* 2016).

Literature Review

Qualitative investigations can inform theoretical understandings of ESRD to support the development of new interventions using patient experiences. A recent online cognitive behavioural intervention (Improving distress in dialysis; Hudson *et al.* 2016a) conducted a literature review into the correlates of distress in dialysis (Hudson *et al.* 2016b). Previous systematic reviews of qualitative research have focused on distress in relation to vascular access, PD and compliance following transplantation (Tong *et al.* 2013; Casey *et al.* 2014; transplant ref). Qualitative research strategies, such as grounded theory, are highly useful in studying the experiences of the chronically ill (Charmaz 1990).

Research into perceptions of chronic health conditions such as diabetes has highlighted the importance of such investigation to reduce stigma. This in turn helps people manage their conditions better and increases understanding on how to encourage lifestyle changes (Anderson-Lister & Treharne 2014). The representation of people with ESRD is a relatively unexplored area compared with other diseases such as diabetes and cancer (Parfeni *et al.* 2013). Qualitative research has been conducted into the IP of patients with chronic conditions such as diabetes (Yilmaz-Aslan *et al.* 2014), hepatitis C (Safo 2015) asthma (Heyduck *et al.* 2015) and rheumatoid arthritis (Simona *et al.* 2016). The findings of the aforementioned studies demonstrate the suitability of IP as a framework for understanding people's knowledge and beliefs around chronic conditions.

In regards to healthcare management decisions, it is vital to have explicit acknowledgment of patients' experiences and needs. However, little attention has been given to improve this understanding particularly among people with ESRD patients (Gregory *et al.* 1998; Guyatt *et al.* 2008). It is vital for health professionals to identify factors which determine successful adaptation (Groarke *et al.* 2004). Understanding the processes people with people with renal disease go through can help healthcare practitioners efficiently manage their patients (Bertolin *et al.* 2008). This understanding can be implemented by practitioners in IP interventions which have been found to have psychosocial and clinical benefit (Broadbent *et al.* 2009).

Gap in the literature

This study sought to understand the nature IP in people who have ESRD using qualitative methodology. Qualitative methodology has utility in investigating experiential processes (Tong & Craig 2014) thus enabling the exploration into previously unexplored psychosocial issues within ESRD (Kaptein *et al.* 2010). Previous qualitative studies within ESRD have focused on adherence (Griva *et al.* 2013; Meuelan *et al.* 2015). One study explored the IP of people with early stage renal disease among a Taiwanese population (Lin *et al.* 2013). The current study sought to expand on this research and add to the qualitative understanding of the psychosocial effects of ESRD using the theoretical framework of IP.

Method

Study setting and participants

To be included in the study, participants had to be in stage five of kidney decline and be receiving RRT. Participants were recruited using support groups for people with renal disease on the internet. Social networking sites have been argued to be an effective strategy for targeting 'hard to reach' populations during recruitment (Baltar & Brunet 2012). For this study the social networking site Facebook was used for recruitment. A researcher used Facebook to search for and join renal support groups. This method was selected as Facebook groups enable members with common interests to find and interact with each other using a common 'wall'. A researcher advertised the study through posting on the 'wall' and inviting potential participants to register their interest in the study via email. This recruitment strategy was also implemented with a Facebook group of a local support group where a researcher was invited to attend and discuss the study in person with members who were not online. Previous research has attributed the success of Facebook recruitment to participants increased confidence in researchers as they show their personal information through their Facebook profile and actively participates in their groups of interest (Baltar & Brunet 2012).

Study design

Semi-structured interviews were conducted using open-ended questions to enable flexibility and prompts to gain deeper insight into participants' experiences. The interview schedule consisted of four sections which focused on how participants perceived their ESRD and their

personal experience of RRT. The interview schedule was developed using elements of the Brief IPQ (Broadbent *et al.* 2006). Table 2 containing the interview schedule is available in the Appendix. The interviews were recorded and then transcribed with any personal information being removed to ensure anonymity.

Data Analysis

Interviews were coded and analysed using constructivist grounded theory (CGT; Charmaz 2006). CGT views grounded theory as flexible guidelines which enabled the use of preconceptions during data collection. This enabled the present study to use the theoretical framework of IP to understand how people with ESRD perceive their illness. Through going beyond the meaning of data, constructivism searches for meaning about individual ideologies, values and beliefs. Informed by CGT, semi-structured interviews were conducted providing participants with the opportunity to express their experiences of ESRD in their own words. Using the epistemology of CGT, this study was able to co-construct an understanding of participants beliefs and actions using the social constructions of people with ESRD (Charmaz 1990). CGT was used as within the context of chronic disease as this understanding provides clinicians with a better understanding of their patients needs.

The analytical process began with line by line coding, where each line of data is coded by an action or word that occurs within the line. This is a crucial phase for developing themes and where the researcher begins to build their analysis (Charmaz 1995). Next, focused coding enabled the researcher to create categories for continually reappearing codes. Categories were created through grouping together codes which appear to explain the data. Constant comparison was used where the coded data was compared for an assessment of similarities and differences (Corbin & Strauss 2008). Theme diagrams were then used to facilitate and finalise theory formation. Throughout this process memo notes were taken to ensure the researcher conducted a focused analysis by recording any interesting information around emerging themes. Memo notes leads directly to theoretical sampling where participants were recruited to clarify and explore emerging themes.

Ethical consideration

Ethical approval for the project was obtained from the University of Liverpool Institute of Psychology, Health and Society Ethics Committee (reference number IPHS-1516-46).

Findings

Eleven participants with ESRD were interviewed using a convenience sample. Participants experiencing a range of RRTs were interviewed including: Transplant (n=4), Home HD (n=2), Hospital HD (n=3), and PD (n=2). The sample consisted of eight men and three women from the North West of England and North East Wales. Participants' age at the time of interview ranged from 28-71 (Mean = 34.45). The number of years since diagnosis ranged from 3-34 years (Mean = 6.09). Demographic details of all participants are presented in Table 3.

In an analysis of the eleven interviews, three themes emerged explaining the IP of people with ESRD:

- 1) Renal Conflicts- (i) hope verses uncertainty, (ii) patient identification
- 2) Forced Adjustment- (i) changes in outlook, (ii) self-initiated change
- 3) Coping- (i) social support, (ii) attitudes

Renal Conflicts

The theme of Renal Conflicts encapsulated a variety of issues patients faced regarding the IP dimensions of Timeline and Identity. A reference to the dimensions of IP is available in Table 1.

(i) Hope verses uncertainty

Participants expressed a struggle between the hope verses uncertainty of transplantation, a theme which has been previously identified in people who have had transplants (Moran *et al.* 2011). The irreversible and lifelong nature of ESRD meant transplants were of considerable interest to many, as it has been suggested patients prefer a life with a transplant over a life on dialysis (Keogh & Feehally 1999). The potential for transplantation gave participants hope of an escape from dialysis, which was linked to the perceived Timeline of illness:

It's long term for the rest of my life if I don't get a transplant. Until the day I die unless I get a transplant (Female 5, Home HD)

Uncertainty is a salient issue amongst the chronically ill (Mishel 1999). Participants expressed their uncertainty with transplantation in their use of rhetoric. Rhetoric centred on managing expectation and hope through reminders that transplantation is another treatment and not a cure:

Renal failure comes in phase...transplant isn't a cure it's a treatment... (Male 3, Home HD)

Using rhetoric similar to this is linked to the IP dimension of Timeline due to the uncertainty associated with the variable duration of transplants:

...when you get a transplant you think- I don't know how long this thing is gonna last... (Male 2; Transplant)

(ii) Patient identification

Patient identification was found to be linked to the dimensions of Timeline and Identity. In IP Identity refers to the label given to an illness i.e. the medical diagnosis and any symptoms experienced. Previous research has linked having many symptoms with increased depression (Griva *et al.* 2013; Chilcot *et al.* 2011b; Ibrahim *et al.* 2011). However, this study found an additional link between self-identification with ESRD as a result of symptomology. Identities have been found to evolve during the illness experience (Park *et al.* 2009). The conflict between personal and patient identity was significant for participants as the constant threat of

return onto dialysis, even following transplantation, resulted in an identity shift. Participants were found to use disability-first language i.e. dialysis patient rather than person-first language i.e. a person on dialysis:

Once you're a dialysis patient I think you're always one. There's always that little thread that they pull you back in (Male 2; Transplant)

Similar to the Identity dimension of IP, identifying as a patient was found to be linked to participant's physical symptoms:

...your body can't deal with it. Then you start to feel like a renal patient (Female 3; PD).

The relationship between patient identification and symptoms is linked to vintage of dialysis (length of time on RRT, cited in Avram *et al.* 2012) as one participant began PD six months prior to the interview and did not identify as a patient, and preferred the word 'condition' rather than 'illness' to be used during interviews:

I don't see it as a chronic illness...I feel alright (Male 4; PD)

The presentation of physical symptoms made it difficult for participants to maintain a sense of normality whilst on RRT. Some participants were able to limit their time identifying as a patient through choosing PD to avoid identifying as a patient on a weekly basis:

...automatically go into patient mode three times a week instead of occasionally. So when I come to hospital I allow myself to be a patient (Female 3; PD)

Patient identification was found to affect several domains of participants' lives including work:

...then I became known as the taxman with the kidney. The kidney man. So I had this label then. And somehow it got around. The very next meeting I went into with a different accountant 200 miles away, he was like oh <Male 2> how's the kidney (Male 2; Home HD)

In addition to this, male participants disclosed struggles relating to their masculinity:

If I had been born a woman it would be entirely different. Because you don't have to prove your strength...as a man and the society that we live in, it's a huge thing that we have to handle. You know when you go to the pub and you have to arm wrestle I wouldn't be able to because I have no strength in my arms at all (Male 7; Hospital HD)

For male participants, identity conflicts were the result of a change in social roles which were found to be influenced by perception of others. The conflict between remaining independent verses becoming dependent (Charmaz, 1994) was evident among male participants. For example being unable to lift heavy items as a result to his illness, one participant found it difficult to watch his wife take over these duties.

Forced Adjustments

The theme of Forced Adjustments encapsulates the main dimension of IP expressed by participants; Consequences of illness. Participants were required to make adjustments to their lives due to the implications of the restrictions associated with ESRD. For example, the strict diet and fluid restrictions patients must adhere to were found to have social implications as a result of physical inability:

...when your kidneys go you lose energy, you lose strength...and you don't get to do things that you normally do. You're not physically able (Male 1; Transplant)

(i) Changes in Outlook

The aforementioned Consequences linked to the change of outlook experienced by participants:

...couldn't do a lot of what I was used to. So my whole mind set had to change then (Male 3; Home HD)

During interviews the dialogues of patients were similar to the phrase 'Carpe Diem' meaning 'seize the day.' They described the turning points following diagnosis or treatment leading to changes in behaviour. This sense of 'Carpe Diem' is linked to mortality as viewing diagnosis as a 'death sentence' made participants change their outlook:

When you're faced with err you know a death sentence you do have to put things into perspective... (Male 3; Home HD)

For older participants, mortality was significant as they were forced to consider the threat of death which allowed them to change their thought processes. Previous research has identified this heightened awareness of death in Latinos with ESRD (Cervantes *et al.* 2016). This is similar to the theme 'awakening to death' found in research into the identity dilemmas of chronically ill men (Charmaz 1994). This change of outlook allowed participants to retain a sense of Control by exploring end of life protocols during hospital visits.

(ii) Self-initiated change

The beginning of new activities was the main change initiated by participants. This developed from the positive change in outlook experienced, for example participants would use the time spent on RRTs to do something constructive:

I retaught myself how to play the guitar while I was doing it. So I had 3 lessons a day while I was doing the bags. I think for the first year I read a huge amount of books...then I decided no let's do something positive (Male 7; Hospital HD).

Participants were also found to initiate change outside dialysis sessions. For one participant it was important to find an activity that did not depend on her physical health. Based on the suggestion of a Facebook support group user, she joined a choir which she found helpful:

... that's a good way of getting out and meeting people and taking part in an activity that isn't dependent on whether I'm having a good physical day or not (Female 3; PD)

The majority of participants (n=6) were involved in volunteer work, usually through organising patient support groups, dialysis committees, or by fundraising and raising awareness of ESRD. Volunteer work provided participants with a way to remain active due to the flexibility which is not always available with full-time employment. This is important as flexibility was found to be a key factor in maintaining employment on RRTs due to the unpredictable nature of chronic illness (Beatty & Joffe 2006). For some, participation in volunteer work was linked to obligation. This was due to the high level of support and care they received by nurses throughout their diagnosis and treatment:

...you've got to give something back. You can't just take (Male 1; Transplant)**Coping**

(i) Social Support

Participants spoke extremely highly of the nursing staff for the care and support received during diagnosis and treatment:

...the nurses are your emotional support (Female 4; Transplant)

The close bond developed between patient and professional due to the long term nature of ESRD has support within the literature (Sadala et al. 2010; Polaschek 2003) and enables participants to cope with their conditions:

...being a renal patient you do develop these long term relationships with nurses, doctors and patients. So that in itself takes a lot of stigma off treatments and what you're going through becomes abit less scary I suppose (Male 3; Home HD)

Many participants described those involved in their renal experience as a 'dialysis community' or 'family.' Participants were found to draw support from other patients going through similar experiences:

The nurses are great, they're first class, but they've never done it, they've never had it...they don't get it, and I think other patients do (Male 4; PD)

Patient interaction was a key relationship used to cope, with patients receiving and giving support and advice to one another. So much so, participants' described hospital HD as a therapy session. This was important, as although patients were satisfied with the support received from nurses, it was vital to discuss problems and experiences with those going through the same thing. Patient interaction gave participants 'crucial' guidance and information to be able to manage their condition from the true accounts of procedures and complications. This sharing of information was used as coping for participants as it was found to reduce anxiety and normalise experiences. Sharing experiences was found to be an integral factor in patient interaction and allowed participants to cope as it was an added source of support which was available face to face, or online:

...although I've never met them they've been a source of support...they're good for having shared experiences and understanding your anxiety. And good for demystifying clinical things (Female 3; PD)

However, the development of close relationships with other patients was not positive in all instances. Participants disclosed how losing people they became close to was difficult for them to deal with, as it reminded them of their own mortality and emphasised the high risk of death due to life with a chronic illness:

that's begun to bother me, you know, people disappearing" (Male 6; Hospital HD).

As the majority of participants were married (N=8), within the interviews there was found to be an important distinction between spousal support and spousal involvement. Spouses were found to be involved in the participants' renal treatment through attending dialysis sessions. This philosophy of being 'in it together' was found by Skerrett (1998) to be linked with resilience. In a dyadic interview, participants and their family highlighted that the renal journey is not an individual one, but one shared by the whole family. This emulates the findings that cancer is a 'we-disease' due to high levels of family involvement (Kayser et al. 2007).

(ii) Attitudes

Attitudes such as 'luck' were discussed within interviews, and were found to be related to the IP dimension of Causality:

...I think the really unfair thing about dialysis is you don't know what causes it. You haven't done anything to deserve it, it's just like bad luck" (Male 1; Transplant)

Openness was another attitude discussed by participants. The link between the attitude of openness and the disclosure of illness was found to be linked to the IP dimension of Control. The attitude of openness was found to have crucial links to participants' disclosure of their illness to others. Issues around disclosure were identified in relation to meeting new people i.e. employers, colleague and university peers:

you don't look at me and think I'm a renal patient. Nobody knows until I tell them (Female 3; PD).

The discussion of illness experiences within the interview was also found to be cathartic for participants:

I've probably gone for hours. I think it's probably because you spend so long not wanting to talk about it when someone is interested in it I have so much to say that I've never expressed (Female 3, PD)

This can be explained as participants found it frustrating to deal with the reactions of others following disclosure. This led to a reduction in openness and led to the creation of a culture of acceptance:

Stop being the socially acceptable face of chronic illness (Female 3; PD)

Disclosure of illness presented difficulties for patients with genetic conditions such as Polycystic Kidney Disease (PKD), which has a 50% heritability rate to offspring (PKD charity 2014) and those on probationary work contracts. It is important to understand the positive and negative effects of Control as previous research has associated lower mood with lowered beliefs in personal capability (Griva et al. 2013; Ibrahim et al. 2011). Another important factor influencing disclosure was found to be time since diagnosis. During early diagnosis participants commonly experienced denial in reactions similar to the stages of grief (Kubler-Ross 1969). Denial in turn affected a participant's decision-making process in terms of disclosure. This is important as decision making, such as disclosure, was found to give participants a sense of control they otherwise lacked due to the constraining nature of RRT. Participants discussed how they were advised by medical practitioners to try and control aspects of their life on dialysis. This links to aspects of person centred care (PCC) which was found to be important for Control. A recent review found patient engagement to be a vital element of PCC (Bear & Stockie 2014). For this to happen, both patients and their families must become 'health literate'. This involves confronting and accepting the nature of ESRD to achieve control:

...if they say to you never eat bananas again, you'll think well no I'm going to eat whatever I want. If they say to you, your kidney can't deal with potassium and if it gets dangerously high you'll have a heart attack, then you start finding out what foods have potassium in because you don't want to have a heart attack (Female 3; PD)

Implementations such as demystifying clinical terms in practice would benefit patients enabling them to take more control over their medical decisions:

...they go on about different levels, but they don't tell you what they mean...they don't tell you much about what they check (Female 2; Home HD)

Discussion

The purpose of this study was to use qualitative methodology to examine the nature of IP in people with ESRD. Three interlinking themes of Renal Conflicts, Forced Adjustment and Coping emerged from the data representing the experiences of people on RRT. Overall, the most substantial dimension of IP was Consequences due to the amount of forced adjustments experienced by participants. Supporting the work of previous research the present study found RRTs result in vast psychosocial restrictions and changes in terms of identity, friendships and physical ability (Mariotti & Carvalho 2011). Control was another dimension of IP discussed. Providing supplementary information to the findings of Chilcot (2012), although participants were found to have no control over the physical aspects of their illness, they compensated through controlling disclosure and medical decisions regarding end of life and RRTs. Findings from the current study suggest participants regain a sense of control through decision-making processes such as disclosure. Through recruiting participants on a

variety of RRT this study expands on the results of previous research into PD only where control was attained through adjusting PD routines in response to the recognition of symptoms (Tong *et al.* 2013).

In regards to Timeline, participants understood their condition was chronic, and although transplantation gave them hope of escaping onto dialysis, they accepted they would always be people with renal disease. The unpredictable nature of transplant failure has been previously identified to monopolise patients' lives (Jamieson *et al.* 2016). This resulted in dynamic shift in identity in participants who have experienced transplantation which can be explained by the constant threat of return onto dialysis as transplantation remains a RRT and not a cure.

It is vital to understand how patients perceive their illness to identify factors that determine successful adaptation (Groarke *et al.* 2004). IP have been found to change over time (Hagger & Orbell 2003). One suggestion for future research would be to use longitudinal designs to discover how perceptions change with vintage of dialysis, especially in light of this studies finding that patient identification was linked to symptomology. This understanding will aid healthcare professionals to manage their patients (Bertolin *et al.* 2008) and to implement successful interventions (Broadbent *et al.* 2009). Interventions such as 'Improving distress in dialysis' (iDiD; Hudson *et al.* 2016) are currently being trialled and may benefit from the qualitative data reported in this research.

Limitations

The main limitation of this study is the recruitment methods used. Authors have raised concerns about the usefulness of online methodologies due to the sample bias in terms of demographic characteristics in the internet population (Coomber 1997; Stanton 1998). Advertising the study on social media sites and patient support groups may attract participants who have a predisposition to talk more openly about their experiences and to seek support which would facilitate their adjustment. This limitation would mean the recruitment process may overlook people who would not take part in an interview due to their own personal characteristics, despite their experiences being just as valuable. The literature surrounding the utility of online recruitment is less extensive than other areas of research e.g. online data collection (Wilson & Laskey 2003; Benfield & Szlemko 2006; Davidovich & Uhr 2006) thus is an area of interest for future research.

Given the sampling method, we did not have access to clinical data in order to evaluate the "representativeness" of the same in terms of clinical characteristics. Therefore the implications of these results may not be generalizable across the ESRD population.

Due to the time constraints of this project, we were unable to seek Public and Patient Involvement (PPI). PPI would have produced valuable feedback during the generation of the interview schedule. Future research is advised to adopt PPI during the developmental phase of research, specifically in the context of long term conditions in accordance to best practice guidelines.

Implications for practice

The findings from this study have important implications for practice. From an analysis of the interviews the close relationship between patients and nurses was evident. Practitioners could utilise this relationship to involve patients in their care, in accordance to Bear and Stockie's (2014) suggestions to implement PCC. As patient interaction was found to be an integral coping resource, practitioners could encourage sharing first hand experiences to reduce anxiety in newly diagnosed patients. This could be done by creating hospital specific support group online to introduce patients, or by implementing informal events for patients and families to meet face to face. This implication supports the work of Jamieson et al (2016) who found patients to communicate with 'renal friends' online. Sharing experiences between patients could also be implemented in patients writing down their personal renal journey for other patients to read. This has two-fold benefits firstly by connecting patients, especially those on home RRTs and patients without access to the internet. Secondly, Frank (1995) believes sharing illness stories provides the opportunity for people to make sense of their experiences. Implementing the expression of illness stories in practice may provide a cathartic release for patients that may facilitate adjustment. This implication supports the findings of Tong et al. (2013) who highlighted the value patients place on communication with one another to share experiences and coping strategies.

Another implication based on the Selection, Optimisation and Compensation model proposed by Baltes and Baltes (1990) would be to advertise activities which do not depend on physical health. Adverting activities in hospitals or support groups in which people with ESRD could regularly attend could improve perceptions of control through not directly suggesting the activities and compensate for any losses as a result of forced adjustments.

Conclusion

The fundamental findings of this study included the high level of Consequences perceived by ESRD patients. These Consequences were linked to the forced adjustment experienced by participants due to restrictions and symptoms. Identifying as a patient was also linked to symptomology, a shift which was evident due to permanence of RRT. Participants were found to have no Control over the physical aspects of the disease however regained Control through decision making and involvement in care. Participants used the close dialysis community which included nurses, patients and spouses as a coping resource and used acceptance to deal with the chronic Timeline of illness. The results of the study have important evidence-based implications for practice from an improved understanding of the how people with ESRD perceive their illness.

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